International Genetic Alliance

"Seeks a world where genetic conditions are understood, prevented, treated, ameliorated and cured"

2011

For members and interested parties

Special Edition
 # 12

Relevance of nutrition for patient and risk groups

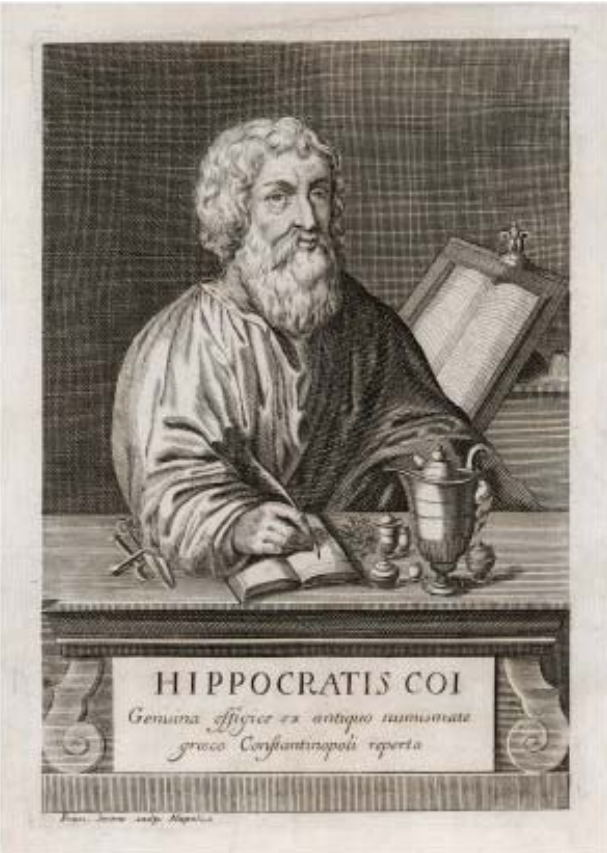
On March 28, 2011 representatives of patient alliances, the International Osteoporosis Foundation, health professionals, and nutrition experts facilitated a Nutrition Summit, linked to Biovision in Lyon (France), the foremost international event for scientists, opinion leaders, and stakeholders in the field of life sciences.

The Nutrition Summit provided a unique platform to discuss the specific nutrition needs and requirements of patients and other people with impaired health, building on the latest science. Leading participants in the summit have now joined forces to publish the enclosed 'call to action' – a set of science-based, cost-effective recommendations to support good nutrition, which will benefit patients, people with impaired health, and other citizens, by having a positive impact on overall public health.

The reason why this topic now is raised is that nutrition itself is not recognized generally as an important topic for most patient groups. While at the same time most patient groups have direct or indirect (latent) nutritional needs.

Introduction

In the past nutrition and pharmacology were seen as complimentary that needed to be used next to each other to improve health of people or to treat diseases. The ancient Greek divided medicine into three categories: diet, pharmaceutical and surgical medicine. Also in so called traditional medicinal systems such as Ayurveda and Traditional Chinese Medicine there is no fundamental difference between both disciplines, and nutrition is a normal part of prevention and healthcare. In the western world, nutrition research and pharmacology developed separately. Rapidly expanding population, economical crisis and international crisis and international conflicts, nutrition first had to supply



Hippocrates (500 BC): "Let food be your medicine and let medicine be your food. Only nature heals, provided it is given the opportunity"

the western world with safe food with enough energy, proteins and essential micronutrients* (N.A. Georgiou et al, 2011,1).

The interaction between pharmacology and nutrition science is on the rise. Nutritional status is considered one of the important determinants of health and disease. Several diseases in our

time have a clear link with lifestyle factors including the diet. There is also increasing realisation that a continuum between health and disease often exists without strict bounderies, especially in chronic diseases. The distinction between foods and drugs follows from the primary goal of nutrition which is to *maintain*, or if possible to *improve health*. This is an essential difference with pharmaceuticals, which are generally developed to *treat, cure* or to *prevent disease*. (N.A. Georgiou et al, 2011, 2)

Nutrition plays a key role in human health and wellbeing. This is true through-out the life-cycle: starting from conception, and later at all stages in life: for babies, infants, adolescents, young and older adults. In the developing world the prevalence of malnutrition is high, primarily because of the limited availability of nutritionally adequate foods. There is however, also a lesser known problem of micronutrient deficiency in the developed world. Although the supply of food can be plentiful, some population groups are not achieving the right level of micronutrients in their diets to support good health.

Scientists, physicians, and public health experts all emphasize the importance of diet in improving human health: an adequate diet providing all essential micronutrients will contribute to not only a better nutrition, but will in the long run also reduce the burden of chronic diseases. It is reported that up to 50% of patients in hospitals suffer from a lack of micronutrients in their daily nutrition. This can compromise the effect of their treatments and leading to poorer patient outcomes and finally additional costs.

Specific population groups such as older people (especially those living in institutions), disabled people and people experiencing an ill-health are vulnerable to malnutrition. This problem can be addressed through the fortification of foods, which can have a widespread impact in addressing specific micronutrient deficiencies. Population-based approaches are already delivering good results in more than 50 countries worldwide. Examples are:

- Iodized salt to reduce goiter (swelling in the thyroid gland**.
- Sugar fortified with vitamin A to reduce the risk of blindness and child mortality.
- Flour fortified with folate. Folate is important for the development of the brain and the spine during the periconceptional period. Optimal intake reduces the risk of neural tube defects such as spina bifida and anencephaly.
- Milk and dairy products fortified with vitamin D as vitamin D is essential for healthy bone and for older people to reduce the risk for osteoporosis.
- Dietary approaches in individuals such as diabetes and patients with renal diseases.

It is important to scale up solutions such as these for different populations groups and to give a higher priority on the role of nutrition in supporting public health. It will improve health and reduce costs.

Relevance of nutrition for patients

The relevance of 'nutrition' for patient groups can differ significantly. Its importance strongly depends on the role nutrition or nutritional aspects can play in the prevention, treatment and management of the disease or disability. Many families affected by a disease are looking for information on how to best manage the disease outcomes of themselves or affected children. Besides the personal interest of many patients also society is interested in optimal health outcomes and healthier longer life, longevity.

So far, only a number of specific disease groups such as Coeliac disease, COPD and Crohn Disease have addressed nutritional issues directly. It is essential, however, that specific disease groups with nutritional problems actively participate in the development of nutritional products.

Identified subgroups of diseases and people

Of course there are specific groups of diseases and people that can benefit from good and optimal nutrition. These are:

- **Specific diseases:** Coeliac disease, Anemia, Obesity, Diabetes, Crohn & Colitis, Asthma, COPD, etc.
- **Perinatal, maternal and older adults:** Nutrition following the life cycle.
- **Malnutrition and nutritional supplements:** HIV/AIDS, Cancer, Pre-and Post operational patients.
- **Nutritional aspects of metabolic diseases:** Phenylketonuria, Mitochondrial diseases, Lysosomal storage diseases, Glycogen storage diseases, Lipid storage diseases etc.
- **Nutrition and prevention aimed at life style**
- **Global World Issues:** Vitamin D and Iodine deficiency

Nutrition in the perinatal period* of pregnancy**

Besides the risks people have to face if they don't have access to sufficient and optimal nutrition during their life, people also are at risk when their physical bodies are developed in the prenatal stage. The periconceptional**** period is the most important period in which reproductive failures originate. These reproductive failures comprise low birth weight, preterm birth, and congenital anomalies and are major contributors to perinatal mortality and morbidity. Maternal nutrition has been recognised as one of the main

environmental factors influencing the development of the embryo, foetus, and placenta with short and long term health consequences. Much knowledge has been obtained on the role of folate in reproduction, but recently the identification of dietary patterns has emerged relationships between maternal malnutrition and pregnancy outcome as well. Outcomes that show optimal nutrition during pregnancy is essential to reduce the risk of birth defects.

The difference in the Push and Pull approach

The push model (see image 1) is a model where the end users are not being involved in the development of nutrients and decision making process of what is important or should be prioritised. It is science and industry who are 'pushing' the research ahead and the end users are waiting until it is ready and can be used.

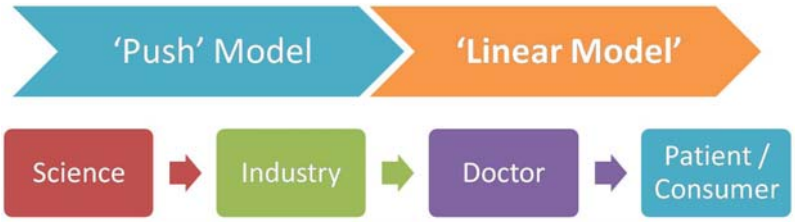


Image 1: Push Model

The pull model (see image 2) shows that there is active interaction between the several parties such as science, industry, doctors and patients/ consumers. The combination of 'evidence-based' scientific knowledge with the 'practice-based' knowledge of patient groups leads to an 'added' value. There are a number of promising examples of this added value from patient groups in the drug development process (long-term financing biobanks, active involvement in clinical trial design etc.). In the pull model all parties are continuously interacting with each other to set priorities. The advantage is no products will be developed that are not really needed by patients and consumers. Via this model also the needs of patients and consumers can be addressed appropriately without much delay and with the involvement and expertise of all parties, so time is not wasted and experience and knowledge well used. The 'pull' approach can be triggered by stories from 'expert patients' in areas where nutrition plays an important role like in celiac disease. The Dutch Health Council also recommends the pull approach in her reports on 'Agenda Medical Biotechnology' (2006) and 'Medical products: new and needed' (2011)).

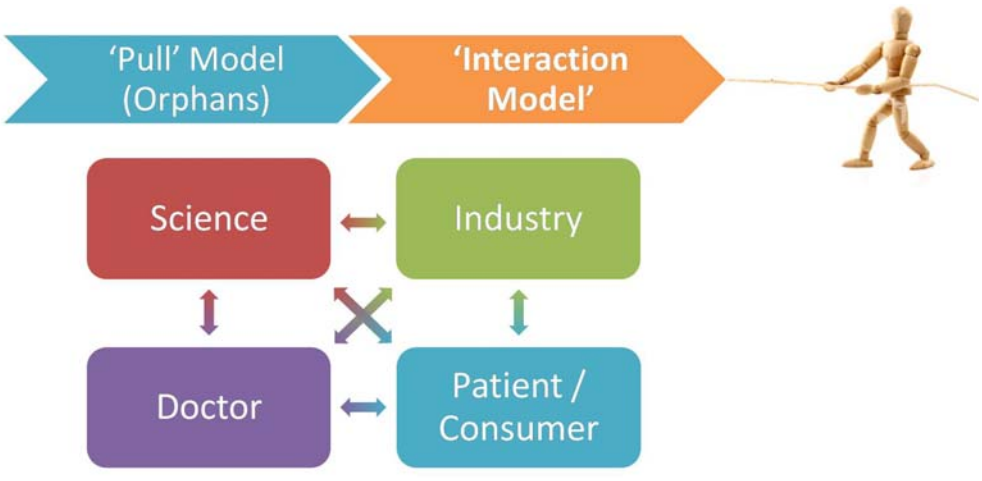


Image 2: Pull Model

Changes needed in Health policy

To make the nutrition aspects in diseases a success some related health policy issues should be addressed:

- Reimbursement of nutritional dietary supplements by health insurers.
- Credibility of health claims on nutritional products.
- Life style coaches to address overweight problems as is done by Dutch Health Care Insurances.

Statement of the International Genetic Alliance

We strongly support partnership approaches to achieve this, involving politicians, patient alliances, academia, regulatory bodies, and the private sector including industry to develop, implement and sustain effective dietary approaches and food programs. Only such a joint effort will contribute to achieve the 'Millennium Goals' as defined by the United Nations such as end poverty and hunger, improve child and maternal health. In addition, in the Copenhagen Consensus 2008 leading economists proposed appropriate diets and micronutrient interventions to be very cost-effective measures to foster economic growth in the developing world and likely reduce healthcare costs in the developed world.

We are specifically calling on national and international policymakers to play their part by:

- Implementing awareness campaigns informing the public patient groups about

the importance of micronutrients for a daily balanced diet.

- Ensuring that healthcare providers and other health professionals understand the major health consequences of inadequate micronutrient supply in the diet.
- Foster research in the field of nutrition to address knowledge gaps and elaborate evidence -based concepts to improve nutrition.
- Providing clear, fact-based information on micronutrients, and promoting their potential to reduce the disease burden on patients, and save on future health care costs.
- Establishing a legal framework which ensures that health professionals can offer the most effective micronutrient nutrition care programs.
- As signatories to this 'call to action', the organizations below are committed partners, who will support the efforts of policymakers by delivering science-based nutritional advice to maintain dietary health for the general population, for patients, people with impaired health and people at risk, communication activities and awareness raising initiatives on key subjects in nutrition, and by creating platforms and partnerships between academia, patient groups, authorities, and industry to highlight the importance of optimal nutrition, nutritional solutions and food safety.

We strongly believe that public private partnerships are the most effective vehicle to deliver improvements in micronutrient intakes and health, and we remain committed to promoting the best nutritional solutions to meet the needs of patients and other people with impaired health, other citizens and society.

Lyon, 28 March 2011

International Osteoporosis Foundation (IOF)
International Genetic Alliance (IGA)
EGAN - Patients Network for Medical Research and Health
Preparing for Life
Sight And Life
GAIN - Global Alliance for Improved Nutrition
Kraft foods
Unilever
DSM

Resources

- Cees Smit
- Ysbrand Poortman
- Georgiou, N.A., Garssen, J.R.G., Witkamp, R.F., 2011. Pharma-nutrition interface: The gap is narrowing. European Journal of Pharmacology 651, 1-8.

Notes

* Micronutrients are nutrients someone needs throughout life in small quantities to orchestrate a whole range of physiological functions, but which the organism itself cannot produce such as vitamins and carotenoids (Alpha-carotene, Beta-carotene, Lutein, Zeaxanthin etc.).

** Worldwide over 90% cases of goitre are caused by iodine deficiency.

*** The perinatal period is the last stage of pregnancy in which the internal organs will be completed. It spans a period from 28 weeks after conception through one week after birth.

**** The periconceptional period is defined as one month prior to pregnancy through the first trimester.

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